

The care of the limb deficient child in Venezuela

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Abstract

An overview of the situation in Venezuela is made by sampling the cases of congenital limb deficiency treated at the Hospital San Juan de Dios in Caracas from 1961-1989. The major longitudinal deficiencies are analysed.

The socioeconomic situation of the patients is of most importance being the cause of final decisions in relation to surgery, the ordering of prosthesis and orthosis, supplied mainly by the Venezuelan Institute of Social Security (IVSS), the maintenance of these items and the possibility of travelling to the hospital for diagnosis, treatment and follow-up.

All these transform the situation from a medical problem into a socio-economic problem typical of a third world country.

Introduction

Patients suffering from limb deficiencies present at birth in Venezuela, come from all over the country, to be seen and treated in the capital city of Caracas, where there are three hospitals able to treat these types of deformities. Of these three hospitals, two are of private administration under private foundations. These two hospitals are: Hospital San Juan de Dios, owned by the catholic order of the Fatebenefratelli Hospitalary Order and the Hospital Ortopédico Infantil owned by a private foundation, the Venezuelan Foundation against Poliomyelitis. The other hospital, Municipal Children's Hospital José Maria de Los Rios, is owned by the Municipal Government of Caracas. These hospitals take care of almost 75% of all children in the country as specialized hospitals. Another similar children's hospital, San Rafael Hospital, is

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located in Maracaibo, the second city of the country, and also belongs to the Fatebenefratelli Order, but children with congenital deficiencies are referred to the Caracas Hospital.

The Instituto Venezolano del Seguro Social (IVSS) is the official national health institution which takes care of the special requirements of those covered even when they are treated elsewhere, or for conditions not treated by other hospitals.

Method

On reviewing patients treated in the Authors' Hospital it was found that the most common congenital limb deficiencies seen were proximal femoral focal deficiency accounting for 27% of cases, and radial longitudinal deficiency (27%) followed by the fibular longitudinal deficiency with 23% and other deformities amounting to 23%. The male sex predominated at 51%.

Most of the patients are seen before two years of age. Amputation if required is not accepted by the parents as a primary choice. They refer other types of limb saving treatment and leave amputation as a last recourse at an older age in case of failure of the treatment selected. Thus the tibial longitudinal deficiency was amputated in 51% of cases, the fibular longitudinal deficiency in 30%, both after other types of procedures were performed and the proximal femoral focal defect was amputated in 15% of cases. In the latter (PFFD) the rotation-plasty was always refused possibly for cultural reasons and a Syme's type of amputation to allow proper prosthetic fitting was performed when required. The age for amputation was delayed until the child could stand or ambulate and very seldom performed as a primary procedure and then only in tibial longitudinal deficiencies where salvage of the limb was

Table 1. Congenital limb deficiencies presented at Hospital San Juan de Dios, 1961-1989

Deficiencies	Number of Patients	Number of Limbs
Proximal femoral focal deficiency	26	26
Radial longitudinal deficiency	26 (11 bilateral)	37
Fibular longitudinal deficiency	22 (2 bilateral)	24
Tibial longitudinal deficiency	17 (3 bilateral)	20
Tibial and fibular shortening	6	6
Total	97	113

recognised by the parents as "very difficult". The cost of the prosthesis or the orthosis required was covered mainly by the IVSS and less frequently by voluntary donations. The social status of the children, according to Graffar was "low". The maintenance and repair of the prosthesis and orthosis was carried out on a very irregular basis due to low financial income, living in places separated from the capital or main cities, low cultural level and poor understanding as to how to care for the items. Patients usually only come to the hospital when they require a new prosthesis or orthosis, because of total destruction or change for a larger size.

Material

A retrospective study was made on the records of patients seen at Hospital San Juan de Dios from 1961 to 1989 with a diagnosis of congenital deficient limb. It is to be stressed that surgery in this hospital is either free of charge, if the patient status requires it or according to different rates, depending on the patient's financial position, but always much cheaper than the cost of the same procedure in a private clinic. The IVSS covers the cost of those patients operated at their institutions under their affiliation. Other costs are covered by funds of private institutions or charity organisations.

In each case the authors determined:

1. type of congenital anomaly;
2. affected limb;
3. age when first seen;
4. sex;
5. social class (Graffar);
6. amputations, time and level;
7. orthosis or prosthesis and evolution.

A total of 97 patients were diagnosed with a congenital deficient limb. The deficiencies presented are shown in Table 1.

Proximal femoral focal deficiency

A total of 26 patients were seen, 14 left and 12 right, 14 were males and 12 females.

Age when first seen, between one month and 11 years with a mean of 2.5 years.

Social Class: 20 "low" and 6 "medium".

Amputation: Rotationplasty was always refused. All cases had a stabilization of the hip and one had a through-knee amputation and 5 a Syme's. The rest refused and wore special custom built prostheses.

The compensatory special orthoses and prostheses were obtained mainly by the IVSS (16 cases), by private donations in 8 cases and acquired by the patient or the family itself only in 2 cases. The maintenance of the prosthesis or orthosis is mostly irregular, generally the patient or family repair the item with easily obtainable hardware, only coming to the hospital for a new one.

Radial longitudinal deficiency

Total patients seen 26, with 37 affected hands. Age when first seen ranged from two months to 12 years. Once the deformity is corrected with gentle manipulation and a plaster of Paris cast, the correction of the deformity is maintained with Orthoplast splints and physiotherapy and occupational therapy is started as soon as possible to improve musculature and increase function. Up to 1983, cases requiring surgery were operated according to Riordan procedure (Faldini, 1957) but since 1984 early cutaneous Z-plasty at an early age is being done with better results (Celis and Fernandez-Palazzi, 1984).

Phocomelias

Most children refuse prostheses. Early teaching of foot use is established and thus the prostheses are used mainly by girls for cosmetic reasons.

Fibular longitudinal deficiency

Some 22 cases were seen, 9 left, 9 right and two bilateral. Age first seen ranged between 1 month and 16 years. All cases were "low class" (Graffar).

Above-knee amputation was performed in one case, below-knee in three cases and at Syme's level in three cases. The rest wore compensatory orthoses when required. Prostheses and orthoses are always supplied by IVSS.

Only half of the patients came regularly to follow-up because of other concomitant problem requiring consultation. The rest only came when a new prosthesis or orthosis was required.

Tibial longitudinal deficiency

A total of 17 patients were seen with 3 bilateral making a total of 20 cases, 10 legs were right and 10 left, 10 patients were boys and seven were girls. Age first seen ranged from one month to seven years.

Amputation level was in 8 cases through-knee, 3 cases had a Syme's amputation, 4 cases correction of the foot with talectomy (to allow for orthosis) and the rest refused treatment and disappeared from follow-up.

Concomitant shortening of tibia and fibula

A total of 6 patients presented, 4 boys and 2 girls. Age first seen ranged from two years to six years. All treated by compensatory orthosis supplied by IVSS.

Discussion

Taking the material seen at the Hospital San Juan de Dios as a statistically significant sample of the situation of the congenital deficient child in Venezuela some statements of importance can be made in conclusion.

Almost all patients belonged to the "low class" (70.73%), being mostly from rural areas. The long distance from the treatment centre is the most important cause of difficulty in the treatment, either from the impossibility of assistance to reach the special clinic because of the distance, or lack of money to cover the fare. Those living in big cities or the capital are also in the very low income population and are not able to assist or to buy the prosthesis or orthosis in cases not covered by the IVSS, and rely on charities or private donations.

When the prosthesis or orthosis needs to be repaired this is done by the patient or the family with materials obtained in normal hardware shops. Lower limb affected children had in 64% of cases a compensatory orthosis indicated and 36% a prosthesis. Of these the IVSS covered 60% of the prostheses or orthoses, 36% were obtained through private donations and only 4% were obtained directly by the family. The follow-up of the cases was also difficult and 10% of patients never came back after the first visit.

The above facts transform a medical problem into a social problem.

In the hospitals with special clinics for congenital deficient limbs and prosthetics and orthotics the treatment given to the patient is the most appropriate according to the social, cultural and economic limitations characteristic of the country, and allows the child to be reinstated to society and to lead a relatively normal life.

Note on situation in Argentina

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The diagnosis and treatment of children with congenital deficiencies in Argentina is changing due to many factors, scientific advances, technological advances specifically in the medical world, equipment, rehabilitation, changes in socio-economic conditions and other factors typical of the rest of Latin America.

Historically in Argentina, institutions that took care of the treatment of congenital limb deficient children were private, non-profit making organizations such as ALPI (Asociación Para la Lucha Contra la Parálisis Infantil — Association Against Poliomyelitis) in Buenos Aires and CERENIL (Centro de Rehabilitación Para Niños Lisiados — Rehabilitation Centre for Crippled Children) in Mar del Plata, which with its funds covered the necessary equipment required for comprehensive treatment. Institutions similar to the CERENIL were created in the principal cities of the country in the 1960's and a fellow was sent from this organization to be trained in design and construction of prostheses and orthoses in Chile and the U.S.A. so starting in 1966 a model pilot factory in Argentina.

The National Commission on Rehabilitation (Comisión Nacional de Rehabilitación) created

in 1960 wishing to systematise the treatment of all patients with disabilities of the locomotor systems created the school for prosthetics and orthotics that produced free of charge for the patient the prosthesis or orthosis required by him.

From 1970 the social organizations and systems of organized mutual aids, under pressure from the clients, started to provide orthoses and prostheses generally under agreements with private orthopaedic companies.

Nowadays patients with congenital malformations are treated in private or public institutions not separately. Lamentably there are only very few of such organizations able to give a comprehensive treatment similar to that given in more industrialised countries. Nevertheless the technical ability and capacity of the prosthetic technicians can be compared with anywhere in the world.

The Dirección Nacional de Rehabilitación Psicofísica (National Direction of Psychophysical Rehabilitation), the Dirección Nacional Protección al Discapacitado (National Direction of Protection to the Disabled) and the Dirección Nacional de Emergencias

Sociales (National Direction of Social Emergencies) are state owned organizations in charge of providing pecuniary aid and paying for prostheses and orthoses and special vehicles, and other aids for disabled patients who are without economic resources. The Municipal and Provincial Governments also assign human, physical and monetary resources for assistance and equipment to these patients in co-ordination with co-operative family organizations and beneficent institutions.

From the demographic point of view, after the increased incidence of these pathologies due to Thalidomide, nowadays limb deficiencies are considered non-frequent malformations and there are no official statistics of the incidence in Argentina.

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